

# **The Caregiver**

## **Newsletter of the Duke Family Support Program**

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### **INSIDE THIS ISSUE**

- 3 Genomic Medicine: Defining Risks to Improve Care**
- 5 Alzheimer's 2004: Targeting the Epidemic**
- 6 Interpreting Risk Factors for Dementia**
- 9 NC Leads the Way**
- 10 Help NOT Wanted**
- 12 Sleep Changes in Alzheimer's Disease**
- 15 Grandpa**
- 18 She Belongs**

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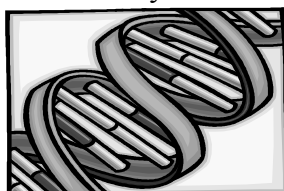
**NORTH CAROLINA ALZHEIMER'S ASSOCIATION NEWS**

**Eastern NC Alzheimer's Association** There are 15 memory walks taking place this fall throughout Eastern NC. To register for the walk nearest you, call (919) 832-3732, or visit [www.alznc.org](http://www.alznc.org); October 30-31, 2003 - The 8<sup>th</sup> Annual Conference on Dementia "Making a Difference in Dementia Care: Applying the Tried, the True and the New." Call 919-832-3732 or (800) 228-8738 to register or for further information.

**Western Carolina Chapter Alzheimer's Association – Mountain Region Caregiver Conference**, November 5, Black Mountain; **2<sup>nd</sup> Annual Candlelight Reflections-The Spirit of Caring: Best Practices for Connecting Congregations and Families Living with Dementia**, November 13, Charlotte, morning conference; **Spring Education Conference 2004: The Many Faces of Dementia**, March 11, Charlotte Convention Center; Memory Walks are being held this fall. Call Chapter Office or access website for information.

## Genomic Medicine: Defining Risks to Improve Care

Donald E. Schmechel, MD, Professor and Director  
Joseph and Kathleen Bryan Alzheimer's Disease Research Center  
Duke University Medical Center



### Good News

The Human Genome Project is finished. The Project provided a map of the human genome -- the DNA sequence of the 22 pairs of normal chromosomes and the two sex chromosomes. This project succeeded in identifying the basic sequencing of some 3,000,000,000 basepairs (the basic letters of the genetic code) and the roughly 30,000 basic genes in the human genome. This is the good news.

### Bad News

The bad news is that this sequence was based on the pooled DNA of a few individuals. There are many polymorphisms or variations of the actual DNA sequences for each individual. In addition, the basic messages that are read from the DNA sequence may be spliced differently during the translation process from DNA into protein structure. This results in many more than 30,000 different varieties of proteins and peptide sequences. To further complicate the picture, proper timing of this reading and translation process is essential, particularly during development and during injury response. Finally, there is a very complex process of regulation through feedback and feedforward loops that helps modulate this process in various cells and tissues.

Each cell in the body is a complex factory using up to 10,000 basic housekeeping DNA messages and from 1000-5000 specialized DNA messages that define its general role, cell identity and even what it is currently "up to". Some of the most complex cells in the body are nerve cells and immune system cells. It is no accident that dementias of middle to late life, and in particular, Alzheimer's Disease (AD), represent disorders involving neurons and immune system cells.

### Defining Individual Risk

Despite known individual variations, these advances in genetics now offer the possibility of defining risk of disease for particular individuals and of defining further possible positive and adverse effects of treatments and medications. The most striking example of a common gene in human disease risk is the apolipoprotein E gene, a cholesterol transport gene, whose three common variants in humans, named 2, 3 and 4, alter risk for a number of illnesses. This is just one of many discoveries before, during and around the human genome project that highlight the benefit of the DNA revolution that began in 1954 with the description of the structure and coding of DNA.

These discoveries and the enabling technology have led to the concept of genomic medicine as a new type or practice of medicine. What would it look like?

**A Genomic Medicine Clinic**

For common diseases like AD, a genomic medicine clinic would establish the genetic background and vulnerabilities that contribute to disease for each and every patient. Each patient would provide a blood sample with DNA (white blood cells from whole blood), a small tissue sample or even scraping of cells from the inside of the cheek. This sample would be amplified with PCR technology to multiply the individual's DNA for reading and interpretation. Such technologies would probably use 'micro-arrays' similar to computer chips for internalized controls and automated reading.

For AD and related dementias, such genetic information might include an individual's APOE genetic profile, and genes related to cholesterol and lipids, homocysteine metabolism, beta-amyloid metabolism, oxidative stress, enzymes involved in cell defense and many others. These genes would provide an estimation of total aggregate risk of AD both from 'bad' and 'good' genes. In addition, additional genes which influence the response to current medications used in AD, or genes influencing response to drugs soon to be discovered, might be important. For example, consider genes related to drug receptors, metabolism and side-effects.

All of this information is static because it is inherited at birth. It could be transcribed on a microfiche to be kept on the person or in the medical record. This approach implies a very personalized and individualized assessment of each person's risk for more than one disease. In a genomic medicine clinic, this assessment of genetic background would be a one-time visit for a particular individual.

**"If it sounds too good to be true, ..."**

Does this sound too easy and idealistic? It should. It is a common-sense truth of diseases of mid to late life that environmental factors (head trauma, diet, stress, other medical disease, medications, vitamins, hormones, sleep) add to the actual effect and contribution of these genetic factors. Thus, the practicalities of a genomic medicine clinic are complex. Eugene Stead, Duke's well-known emeritus professor of medicine, once said, "the patient will still need a doctor" (or 'health professional') to obtain, to humanize and to translate this information into meaningful form.

Assessment of relevant environmental factors, contributing diseases (stroke, lipid problems, heart disease for AD risk), diet and lifestyle will be essential to interpreting the risk status and treatment program for a given individual.

**The future**

Hopefully, public education about the genomic revolution will help bring about this day of 'genomic medicine' clinics. Such an individualized approach might help prevent disease and lessen the burden of the coming epidemic of AD. However, issues remain with regard to cost-effectiveness, the potential adverse use of DNA information, motivating persons to face their health risks, modify lifestyles and/or comply with medical treatment. The US healthcare system with its ten to fifteen-minute new patient evaluations is unlikely to touch issues of genetic and environmental risk. Genomic medicine would require a major shift in our approach. This new approach is about learning and facing proactively the challenges and risk of aging and human disease, rather than 'cleaning up the mess' left by disease.

## **ALZHEIMER'S 2004: TARGETING THE EPIDEMIC**

**18th Annual Joseph and Kathleen Bryan Alzheimer's Disease  
Research Center Conference  
Duke University Medical Center**

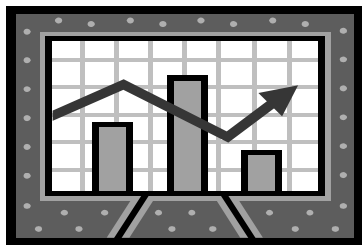
**February 12-13, 2004  
Durham Marriott at the Civic Center  
Durham NC 27710**

**Registration fee \$85 or \$50 for one-day registration  
(Includes meals, educational packet and CE credits)**

**Registration and full program brochure available in  
December, 2003 by mail or on-line at  
<http://adrc.mc.duke.edu>**

**For more information, call (919) 660-7510 or (800) 646-2028  
or write:  
Bryan ADRC Education Core, 3600 DUMC,  
Durham NC 27710**

## Interpreting Risk Factors for Dementia from the Estrogen Plus Progestin Combination Hormone Therapy Study



Ana E. Panduro, Duke Family Support Program  
Gabel Leadership in an Aging Society Intern, 2003

In the May 28, 2003 issue of the *Journal of the American Medical Association (JAMA)*, a research study reported that older women taking estrogen and progestin combination hormone therapy had twice the rate of dementia. But, what does this statistic really mean? Interpreting research can be complex and confusing. Figuring out what the findings mean and how they relate to us is even more difficult. The way findings and conclusions are presented can alter the way we perceive the results and the significance of certain issues. The purpose of this article is first, to provide background on the study and second, to make sense of the data by highlighting the differences between relative, absolute, group, and individual risks.

### **Background:**

The study on the effects of estrogen plus progestin combination hormone therapy was part of the Women's Health Initiative Memory Study (WHIMS), an offshoot study of the Women's Health Initiative (WHI). WHI is a large study sponsored by National Institutes of Health to investigate a number of women's health issues. WHIMS, lead by principal investigator (PI) Sally A. Shumaker, Ph.D., of Wake Forest University School of Medicine, was designed to evaluate the effect of estrogen plus progestin on the incidence of dementia and mild cognitive impairment. Because previous laboratory and population studies of estrogen use had suggested a possible protective effect, this study tested the hypothesis that taking estrogen plus progestin would reduce the risk of developing dementia.

### **Participants**

A total of about 4,500 postmenopausal women participated in this study. This is a relatively large study group, contributing to the significance of the findings. All women study participants were 65 years of age or older, and each woman was screened before the study began to ensure that she did not have dementia.

### **Research Methods:**

This study was conducted as a randomized controlled clinical trial, a research method in which a large group of participants is randomly divided in two groups. Each person has an equal chance of being in either group. This method helps assure that the groups are comparable to one another, given the possibility of known and unknown risk factors for dementia. "Controlled" means there is a comparison group. In this case, one group received the combination hormone pill, and the other group took a placebo. A placebo is a 'fake' drug that looks like the test drug, but should have no effect. The participants did not know whether they were in the group taking the estrogen/progestin combination hormone therapy or in the group taking the placebo.

### **Findings**

- Women taking the combination hormone therapy had twice the rate of dementia (most of which was Alzheimer's disease (AD), compared with women who did not take the combination

hormone therapy. This represents an increase per year from 22 women per 10,000 at risk of dementia in the placebo group to 45 women per 10,000 in the combination therapy group.

- Combination therapy did not protect against the development of Mild Cognitive Impairment, a form of cognitive impairment less disabling than dementia.

### **Making Sense of the Data**

Although the risk of dementia increased when taking estrogen plus progestin combination hormone therapy, the total number of women who developed dementia was low. Data show that in a group of 10,000 women who do **not** take combination therapy, 22 of them will develop dementia. If 10,000 women **do** take combination therapy, 45 of them will develop dementia. The risk of developing dementia does in fact increase by a factor of 2. Although there is an increase of 23 cases, the overall risk for any individual older woman is still relatively small.

In general, an individual's risk of developing dementia doubles approximately every five years after age 65. These data suggest that a 65-year-old woman taking combination hormone therapy has about the same risk for dementia as a 70-year-old woman not taking the combination therapy.

### **Differentiating risk: Relative vs. Absolute; Group vs. Individual**

Relative risk is usually represented as a ratio or a percent. This study compares the likelihood that a woman taking combination hormone therapy will develop dementia to the likelihood that a woman taking a placebo will develop dementia. The findings indicate that older women taking combination hormone therapy had **twice** the rate of dementia compared with women who did not take the medication (those who took the placebo).

An absolute risk is represented in an actual number of health problems that happened or are prevented because of the drug (X number of cases in 10,000). It is a number found by subtraction. In this study, that number was 23 cases. In the placebo group, 22 women per 10,000 were at risk of dementia per year, while 45 women per 10,000 of those taking the combination therapy were at risk. The difference between these two groups is 23, and represents an increase in absolute risk for women taking combination hormone therapy.

Most research gives risks in terms of a lifetime and in terms of group risks. An individual's chance of getting a certain disease is usually much lower than the reported group risks. Although an individual's chance of developing a dementia in this study is low, there are other known risk factors for AD. Advancing age and a family history of AD are the two strongest risk factors (See Alzheimer's Association News Release, August 18, 2003 at [www.alz.org](http://www.alz.org)). One's likelihood of developing Alzheimer's disease doubles every five years after age 65. Having a parent, grandparent, brother or sister with Alzheimer's disease also increases one's individual risk for AD relative to someone who does not have any close family members with AD.

### **The Bottom Line**

The Women's Health Initiative Memory Study (WHIMS) on the effects of estrogen plus progestin combination hormone therapy studied only the effects on postmenopausal women who were 65-years-old or older. The effects for women taking estrogen before age 65 years are unknown from this study, and these effects may be different. What if specific hormone therapies are protective or increase risk for AD depending on when the hormone (s) are taken, the dosage, or the duration of use? One might also question the effects of the progestin.

WHIMS was a large, well-designed study, but questions remain about estrogen's protective or risk factor effects for AD. At this point, there is no research justification for the use of combination therapy just to protect against AD.

**Stay Tuned**

The 18<sup>th</sup> Annual Bryan Alzheimer's Disease Research Center Conference (see p. 5) will feature current unanswered questions in AD, like the estrogen story. Plan to attend for "more on this story" and on other complex questions for research and care.

**Research Headlines: Points to Ponder**

- One study cannot prove anything with certainty. Health advice should have an evidence base from more than one study.
- There is a difference between statistically significant findings and clinically significant findings. Clinically significant findings are those physicians can use in determining treatment options.
- There is a difference between "associated with" and "caused by". AD is associated with advancing age and family history, but no single risk factor **by itself**, except for rare genetic mutations, can "cause" AD.
- There are few simple conclusions about complex late-life disorders like AD.

For more specific tips on evaluating research, see the American Federation on Aging's new website: [www.healthcompass.org](http://www.healthcompass.org)

**Complexity**

Everything is simpler than you think  
and at the same time more complex  
than you imagine.

- John Wolfgang Von Goethe

**MEMANTINE****FDA Advisory Committee Recommends Approval**

- If Memantine is approved by the FDA, it will be the first drug treatment indicated for **moderate to severe** Alzheimer's disease. The four currently approved drugs (cholinesterase inhibitors) are indicated for people with mild to moderate AD.
- Memantine has a different mechanism of action (glutamate system) in the brain and raises the possibility that its safety and efficacy could be tested further in combination with other approved AD treatments.

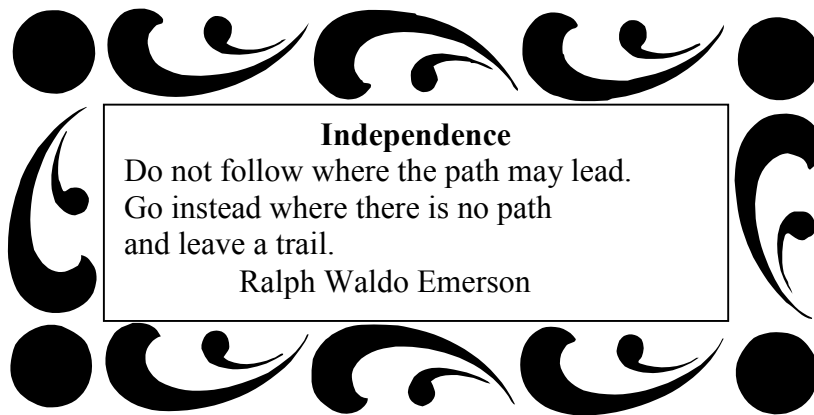


## NORTH CAROLINA LEADS THE WAY

Congratulations to the NC Family Caregiver Support Program for its creativity and leadership. The Administration on Aging (AoA) adopted the NC Family Caregiver Support Program logo as the National Family Caregiver Support Program logo. AoA then chose the September, 2003 North Carolina Conference on Aging in Charlotte as the last of five national Town Hall listening sessions culminating in a September, 2003, national conference on "Creating Caring Communities." The U.S. Assistant Secretary for Aging, Josefina Carbonell, heard testimony from NC family caregivers and leaders in aging. See the NC logo and the premier NC family caregiver website at [www.fullcirclecare.org](http://www.fullcirclecare.org) or [www.dhhs.state.nc/aging/fcaregr/fchome.htm](http://www.dhhs.state.nc/aging/fcaregr/fchome.htm).

NC's Family Caregiver Support Program is hosting three **Caregiver in the Workplace** Forums the week of October 21, 2003 in Wilmington, Asheville and Charlotte. "**Aging, Caregiving and Employee Productivity: Can Everybody Win?**" targets 10 major employers in each county. For interesting background information, see the June, 2003, *The Metlife Study of Sons at Work: Balancing Employment and Eldercare* ([www.caregiving.org](http://www.caregiving.org)).

NC's UNC-TV is also leading the way. The state's public TV station was selected for a national outreach grant in association with a major national public television documentary on Alzheimer's Disease scheduled for **January 21, 2004, 9-11 pm** and titled – **The Forgetting**. Stay tuned for more information at [www.uncvtv.org/outreach](http://www.uncvtv.org/outreach) or check *The Centerpiece* free monthly magazine of UNC Public Television.



### Duke Again Ranks Sixth in Best Hospitals



For the fourth consecutive year, Duke University Medical Center has ranked sixth on the *U.S. News & World Report* **Honor Role** of best hospitals. The annual *U.S. News* rankings highlight 17 specialties. Duke was ranked in 16 of these: 5<sup>th</sup> – **Geriatrics**; 10<sup>th</sup> – **Psychiatry**; 13<sup>th</sup> **Neurology & Neurosurgery**.



**“Help NOT Wanted”:  
Tips on Getting Help for Family Members when They Refuse**

Crystal Massey  
NC State University BSW Intern  
Raleigh, NC

In care relationships, it often takes an outside perspective to identify areas where additional assistance may be useful or even required. Whether you are a caregiver, friend or family member of a caregiver, you may recognize a need, but encounter reluctance, when you suggest extra outside help. First, recognize that this reluctance is common.

There are as many reasons for reluctance to accept assistance as there are families providing care. Often, a primary family caregiver simply does not see a problem. It is easy to become so immersed in daily care that you “don’t see the forest – just the trees”. If this is the case, gently offer your observations and suggestions.

Caregivers may be reluctant to accept help because of practical reasons. The prospect of entering “the system” to seek assistance may be overwhelming. They may be daunted by the anticipated cost or endless intrusive red tape associated with seeking outside help. They may be waiting for more family members or close friends to “chip in” first.

Emotional issues may prevent caregivers from seeking help. Some husbands and wives believe it is their duty or obligation to provide care. Some family caregivers feel guilty about needing help in providing intimate personal care for a husband or wife of many years. They may feel defeated or too proud to admit that they can’t do it all alone. Some families see help as unjustified outside interference. They may suspect outsiders will judge them as “unloving or inadequate”. Failure to seek help may also be driven by fears. Some families trust only their own ability to provide the best care for the people they love. They are afraid that outsiders will not be as reliable, patient or gentle. Often, these families fear that allowing strangers inside the home will make them vulnerable to theft.

Approaching a caregiver about seeking outside help can be touchy and sensitive. Here are eight tips for addressing the issues:\*

- 1. Decide whether a problem truly exists.** Make careful observations. Does the situation make you uncomfortable, or is there a valid reason for concern (issues of abuse, safety, illness of caregiver)? Respect the caregiver’s choices if they are legitimate.
- 2. Earn the right to talk.** Participate in care in any way that you are able. Having actually done part of the work gives you an “inside view” of the situation. Your thoughts may be better received if you can give firsthand accounts.
- 3. Pick the right time to talk.** Avoid stressful times or times when tension is otherwise high. Don’t list demands or give instructions, but instead offer suggestions. Ask how you might be able to help.

4. **Deal with the reasons behind reluctance to seek help.** Address fears and perceptions. If financial issues are a concern, suggest feasible ways to pay for care.
5. **Use “I feel” statements when talking with the caregiver.** Talk about your feelings rather than what the caregiver “should” or “should not” do.
6. **Begin Small.** Suggest a trial period with assistance in one small area. Do not overwhelm the caregiver with many sudden changes.
7. **Use Allies.** If the caregiver does not agree with you, it may be helpful to enlist the help of trusted doctors, nurses, clergy or other family members/close friends.
8. **Do not make promises that you can’t keep.** Never offer to provide the help needed or pay for services unless you are sure you can maintain your help for the long haul.

Remember, helping is not meddling. Respect the caregiver’s choices, but always put the health and safety of the care receiver and the caregiver first. If there are signs of danger or neglect, you may call Adult Protective Services. This agency is authorized to assess the situation and intervene if needed to insure that necessary care is provided.

\* Some points excerpted with permission from: Newsletter of the Alzheimer's Association: Northern California Chapter. (Fall 2000). *When Caregiving Parents Resist Help: Dealing with "Dodgy" Parents.*

### *Criticism*



He has the right to criticize  
who has the heart to help.

*Abraham Lincoln*



### *Change*

Some people change  
when they see the light,  
others when they feel the heat.

- *Caroline Schoeder*

### *Work*

The world is full of willing people,  
some willing to work,  
the others willing to let them.

- *Robert Frost*

# Facts:

## About sleep changes in Alzheimer's disease

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This fact sheet is prepared in consultation with the Alzheimer's Association Clinical Issues and Interventions Work Group. The information provided does not represent an endorsement of any medication or nondrug sleep intervention by the Alzheimer's Association. Updated April 15, 2002.

### **The nature of sleep changes in Alzheimer's**

Scientists do not completely understand why sleep disturbances occur in people with dementia. Sleep disturbances associated with Alzheimer's disease include increased frequency and duration of awakenings, decrease in both dreaming and nondreaming stages of sleep, and daytime napping. Similar changes occur in the sleep of older people who do not have dementia, but these changes occur more frequently and tend to be more severe in people with Alzheimer's disease.

Some people with Alzheimer's disease sleep too much while others have difficulty getting enough sleep. When people with Alzheimer's cannot sleep, they may wander during the night, be unable to lie still, or yell or call out, disrupting the rest of their caregivers. Some studies have shown that sleep disturbances are associated with increased impairment of memory and ability to function in people with Alzheimer's. There is also evidence that sleep disturbances may be worse in more severely affected patients. However, a few studies have reported that sleep disruption may also occur in people with less severe impairment.

Coexisting conditions may intensify sleep problems for older adults with Alzheimer's. Two conditions in which involuntary movements interfere with sleep are periodic limb movement and restless leg syndrome. Other common conditions that disrupt sleep include nightmares and sleep apnea, an abnormal breathing pattern in which people briefly stop breathing many times a night. Depression in a person with dementia may further worsen sleep difficulties.

Shifts in the sleep-wake cycle of people with Alzheimer's can be severe. Experts estimate that in the later stages of the disease, affected individuals spend approximately 40 percent of their time in bed awake and a significant proportion of their daytime hours asleep. This increased daytime sleep consists almost exclusively of light sleep that compensates poorly for the loss of deep, restful nighttime sleep. In extreme cases, people with dementia may experience complete reversal of the usual daytime wakefulness/nighttime sleep pattern.

### **Treatment of Alzheimer sleep problems**

Although widely used medications can temporarily improve the sleep disturbances of older adults, a number of studies have found that prescription drugs do not improve overall ratings of sleep quality in older people, whether they are living in their homes or in residential care. Thus, the treatment benefits of using sleep medications in individuals with dementia may not outweigh the potential risks. To improve sleep in these individuals, the U.S. National Institutes

of Health (NIH) has encouraged use of the nondrug measures described below rather than medication therapy unless the sleep disturbance is clearly related to a treatable medical condition. It is important that the person experiencing sleep problems be professionally assessed for medical or psychiatric causes for the sleep disturbance before applying any drug or nondrug interventions.

### **Nondrug treatments**

A variety of nondrug treatments for insomnia have been shown to be effective in older adults. These treatments, which aim at improving sleep routine and the sleeping environment and reducing daytime sleep, are widely recommended for use in people with Alzheimer's disease. To create an inviting sleeping environment and promote rest for a person with Alzheimer's:

- Maintain regular times for going to bed and arising.
- Establish a comfortable, secure sleeping environment. Attend to temperature and provide nightlights and/or security objects.
- Discourage staying in bed while awake; use the bedroom only for sleep.
- If the person awakens, discourage watching television.
- Establish regular meal times.
- Avoid alcohol, caffeine, and nicotine.
- Avoid excessive evening fluid intake and empty the bladder before retiring.
- Avoid daytime naps if the person is having trouble sleeping at night.
- Treat any pain symptoms.
- Seek morning sunlight exposure.
- Engage in regular daily exercise, but no later than four hours before bedtime.
- If the person is taking cholinesterase inhibitors (tacrine, donepezil, rivastigmine, or galantamine), avoid nighttime dosing.
- Administer drugs such as selegiline that may have a stimulating effect no later than six to eight hours before bedtime.

### **Medications**

Drug therapy should be considered only after a nondrug approach has failed and reversible medical or environmental causes have been ruled out. For those people who do require medication, it is imperative to "begin low and go slow." The risks of sleep-inducing medications for older people who are cognitively impaired are considerable. These include increased risk for falls and fractures, increased confusion, and decline in the ability to care for oneself. If sleep medications are used, an attempt should be made to discontinue them after a regular sleep pattern has been established.

The table below lists some of the many different types of medications that can temporarily assist in sleep. The list includes drugs prescribed chiefly for sleep as well as some whose primary use is in treating psychiatric illnesses or behavioral symptoms. Although little is known about the safety and effectiveness of medications for treating chronic sleep disturbances in Alzheimer's, all of these medications are commonly prescribed to treat insomnia and disruptive nighttime behaviors in Alzheimer's disease. All of the medications listed here are available by prescription

only and must be used under a physician's supervision. The medication recommended by a physician often reflects the type of behavioral symptoms accompanying the sleep problems.

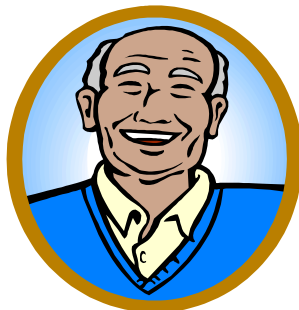
**Some medications commonly used in the treatment of  
insomnia and nighttime behavioral disturbances in Alzheimer's disease**

<b>Drug category</b>	<b>Examples (generic names)</b>	<b>Recommended dose in milligrams/day</b>	<b>Potential adverse effects</b>
<b>Tricyclic antidepressants</b>	Nortriptyline	10 – 75	Dizziness, dry mouth, constipation, trouble urinating
	Trazodone	25 – 75	Dizziness, especially when standing or rising
<b>Benzodiazepines</b>	Lorazepam	0.5 – 2	Lethargy, confusion, unsteadiness
	Oxazepam	10 – 30	Dependence
	Temazepam	15 – 30	Confusion, unsteadiness
<b>Nonbenzodiazepines</b>	Zolpidem	5 – 10	Sedation, confusion
	Zaleplon	5 – 10	Sedation, amnesia
	Chloral hydrate	500 – 1,000	Sedation, nausea
<b>“Classical” antipsychotics</b>	Haloperidol	0.5 – 1.5	Parkinson-like symptoms
<b>“Atypical” antipsychotics</b>	Risperidone	1 – 6	Dizziness, especially when standing or rising; nausea
	Olanzapine	5 – 10	Sedation
	Quetapine	12.5 – 100	Sedation; dizziness, especially when standing or rising

**Where can I get information about other Alzheimer-related issues?**

To obtain information about other important issues related to Alzheimer's disease, please call our Contact Center at (800) 272-3900 or visit the Alzheimer's Association Web site at [www.alz.org](http://www.alz.org).





## Grandpa

©Ana E. Panduro  
Spartanburg, SC 2000

I used to sit on my grandpa's knees and stare endlessly at his head; round, almost a perfect sphere, with an almost complete crown of milky white hair adorning it; allowing his richly tanned skin to peak through the top. And what peaked through, which happened to be most of his head, shone proudly with oil. I never knew whether I wanted to reach out and swirl the oil with the tips of my fingers, or wipe it off and watch it soak up in toilet paper.

His head was just the right size for his extra long ears with the fuzzy gray hairs resting at the bottom. Fuzzy and messy like the silver-white hairs in his eyebrows. His adorable, round face lit up and his lips were brought to life with his contagious grin and hearty laugh whenever he played his mischievous little games on me, or whenever he retold the same jokes again and again.

I used to sit on his knees and stare at his round head and watch as both ends of his lips crawled upwards in opposite directions, gently pushing the flaps of his cheeks higher and higher; giving his face a rounder appearance. "Anita, hold out your hand," he used to say to me, "I have a surprise for you." I always knew that he would cup my little brown hand within his huge ones and carefully curl my tiny fingers over the palm of my hand, as if he wanted me to hold on to what he had given me forever. He never placed anything on my hand and I knew that he never would. It was always empty. However, I always kept my fingers tightly curled as if I did have something and as if I was going to keep it for life. It was a game between us. I played along with him. As soon as he let go of my little hand, I would quickly uncurl my fingers to see what the 'surprise' was. Nothing! I acted shocked, and maybe a bit mad, but I always laughed at the little game he had just played on me. He laughed too.

I used to sit on my grandpa's knees and watch his sparkly head and feel loved. I felt loved by the man whose round head always looked down upon me with a smile, who gleamed with happiness whenever he saw me, who laughed whenever I laughed at his jokes. I felt loved by the grandfather whose strong hands patted my back, swung me around and let me fly, held my ice cream when it got too cold, and were always behind me whenever I climbed the fence in his garage.

I do not get to see my grandfather very often. After all, we do live in different countries. I see him every summer and, on occasion, during Christmas. I saw him this summer, and although it has been years since I have sat on his now frail knees, the top of his head is still shiny with oil.

So much so that it has left behind an imprint on the wall where he leans his head as he watches TV in his room and on his favorite couch. His head is still round and adorned by the now diminishing white crown, and his smile is still brilliant. There is, however, a change about him.

He stares off in a distance, not paying much attention to what goes on around him. His eyes are empty; not focused, not thinking of anything. His lips often quiver and mumble unconsciously. The biggest change is his hands. They shake. They tremble from side to side. They never stop moving. He still pats my back, but instead of one or two hearty pats, ten small, quick, little pats replace them. This is his way of hiding his Parkinson's disease. That and when he sticks his hands in his pockets and applies so much force to keep them from moving that his veins pop out.

I once reached out and placed his baby smooth, little brown hand in mine to stop it from moving. Although fragile and small, it still squeezed mine. His grip was so tight that I felt that as if he were afraid of losing me. For the first time in my life, I felt like a real grown-up, but I did not like it. There I was, with my grandpa, playing the same game we had always played, only in reverse. He was looking up at me with his eyes wide open and observant. Gripping my hand tightly. Seeking love and protection from me. Not wanting to let go.

**Editor's Note:** Ana wrote about her grandfather in Mexico while she was in high school in South Carolina. She is a senior, pre-med student at Duke, and she completed a Gabel Leadership in an Aging Society internship in 2003. She has an expressed interest in geriatric medicine and Alzheimer's disease.

### Gratitude

In our daily lives,  
we must see that  
it is not happiness  
that makes us grateful,  
but the gratefulness  
that makes us happy.



- Albert Clarke



### Happiness

Don't cry because it's over,  
smile because it happened.

- Unknown





***Grandmother and  
Thanksgiving***

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Durham, NC 2002

Thanksgiving puts us  
out of home in the Piedmont  
over the rivers  
and through the mountains and woods  
to Mother's for the night  
and on to Mama's in Kentucky before  
dawn tomorrow,

We go in to see Mother,  
flowers in hand,  
and she's curled up asleep  
her room bright and warm and clean  
the friendly tv cartoon companioning her  
sleep,  
my wife and I talk a bit  
and the eyes stay closed  
so I kiss her,  
her face opens in a smile  
her eyes reacting to our presence  
her words welcoming us with a general  
"That's good,"  
and she slips back into dream  
a smile still on her face,  
the chronic pain from aging bones  
and muscles  
and synapses  
eased by medicine that makes her sleepy,

how blessed we are  
that place and resources and loving care  
can still hold her,  
protect her,  
care for her  
as a mother to a child,  
as the love that has flowed and still flows  
from her as a mother  
flows back to hold her,

while her 92 year old body and mind  
slowly give up the ghost.

***Still All There?***

©Henry Walker 7/31/03

for most of this last decade  
Alzheimer's has been taking Mother away  
and I've worked to get to her still  
and I've worked to figure out what all's happening,

I've written of paranoia and anger,  
the loss of mobility—body and word,  
I've written also, often, of how much isn't lost,

Well-meaning folks have advised me it's not her  
there any more,  
the insidious alchemy of disease changing her at the  
core of herself,  
but my intuition begs to disagree  
as it feels more right to me that self endures strong  
in her  
and that self still is connected to us all  
despite the topsy-turvy tumbling of neurononic  
pathways gone awry,

the most common question to me: "How is she?"  
and close on its heels: "Does she still know you?"

and most seem satisfied with no real answer to the  
first  
just some variation and detail on "She's fine. . ."  
and the answer to the question seems to tell them  
if she's still close enough to be worth care,

even so far along in Alzheimer's cluttered dusk  
my wife and I feel who Mother "Is" is still all there  
hiding away in dreamy sleep  
and when awake without logical, linguistic  
pathways  
to cross the trackless wood  
between her "there" and our "here,"

her eyes and heart can still cross with ease  
and sometimes still even her words mostly work,

she still knows "who" she is,  
it's "where" that scares her,  
not knowing exactly "what" is happening,  
and if we look to her with our heart  
we can still get to a Mother all there.

**She Belongs**

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picture this:

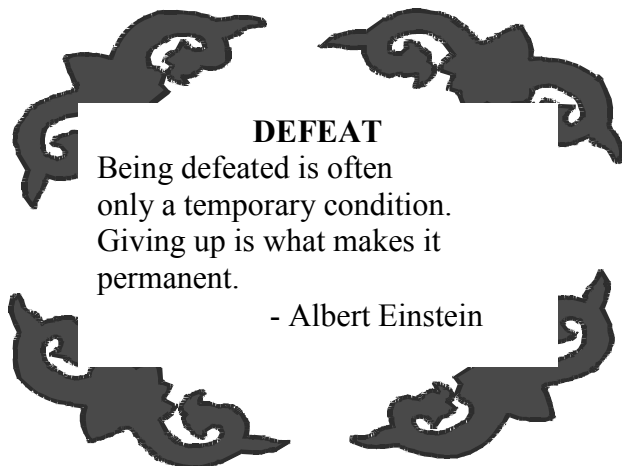
in the early afternoon  
something gets her into a snit  
some inexplicable action done to her (we'd say 'for her'),  
some sense of not being in the right place,  
she half raises out of the bed  
and her finger points at me  
and her words jab at me in protest,

a couple of hours later  
sister, brother-in-law, and I go to her  
and she knows that we belong  
and, if we belong, she does, too,  
and words tumble out of her for  $\frac{3}{4}$  of an hour,  
a long narrative  
explaining to us what all's happening,  
reminding us the children are the most important,  
and beaming brighter with each new family and friend  
who join the circle like bees drawn to the honey of her love,  
smiles and laughs spread among us  
as she holds forth and holds us,

when my cousin tells her her sister and brother-in-law are there  
she quickly retorts: "I know. I was just talking to them."  
though our names fit her tongue only vaguely,

after talking for quite awhile, she announces: "And finally. . ."  
then she looks around and declares:  
"I get a kick out of you all."

We touch and kiss her and make our way away  
and, exhausted, she slips back into a sleep  
we hope is more comforted  
by our being there  
and helping her remember she belongs.





### Have You Heard About?

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Box 3600  
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[www.dukefamilysupport.org](http://www.dukefamilysupport.org)

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